ARIZONA CANCER REGISTRY
ADHS Bureau of Public Health Statistics
1740 West Adams, Room 410
Phoenix, AZ 85007

Janet Napolitano, Governor
Katherine Eden, Director

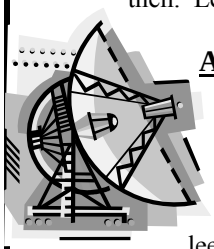
CANCER NEWS AND VIEWS

PUBLISHED BY THE ARIZONA CANCER REGISTRY FOR THE INFORMATION AND EDUCATION OF ARIZONA CANCER REGISTRARS

Volume 14 Number 1 Spring 2003

ANNOUNCEMENTS

The last issue of the CN&V came out was the fall of 2001. As is always the case, a lot has changed since then. Let's stick to the recent changes ...



ACR Staff Changes

Three new registrars started work with the ACR last fall. Many of you met them at the annual meeting. They are Steve Forney, Colleen Zubiate and Kim Nguyen. Judy Orth started in January.

Amy Stoll, MS is the new manager of the Data Analysis and Special Projects Section. Brenda Smith is the new Operations Manager. Nancy Doll, RN, CTR is the new Trainer for the ACR. Also new to the central registry, in the Data Analysis and Special Projects Section, is Dina Hudson, MPH. She comes to the ACR with a background in epidemiology, having most recently worked in sales of orthopedic surgical supplies. Dina's other healthcare experience has been as a data management analyst. She will begin conducting audits for the Arizona Cancer Registry in 2004, after she completes training in the central registry.

New Faces at New Places

Lisa Kershen has accepted the position of Cancer Registrar at Chandler Regional Medical Center. Cherry Miller, CTR, has moved from Banner Good Samaritan to Thunderbird Samaritan Hospital. Banner Good Samaritan has a new Cancer Registry Manager starting. She is Sharon Stapleton, CTR, coming for Rochester, NY. Welcome, Sharon! and thank-you Good Sam for recruiting another CTR to our state. Susan Sullivan, CTR, recently left St. Joseph's for a position at Banner Good Samaritan Medical Center. Charlotte Thweatt, A. AS, Cancer Registrar has joined the staff at Verde Valley Medical Center. Boswell Hospital Cancer Registry happily welcomes Valerie Trotty-Serna, CTR and Mary Valenzuela to their staff. Rick Reynolds, CTR, has temporarily joined the staff at Havasu Regional Medical Center to catch up on casefinding and abstracting. Marilyn Ronci, RHIT, CPCS, Registered Health Information Technician and Certified Provider Credentialing Specialist is scheduled to begin on 3/31/03 at Scottsdale Healthcare as Cancer Registrar II. Welcome and congratulations to all!

Holiday Reminders

Please remember that the ACR will be closed on the following holidays:

- Monday, May 26th, 2003 in honor of Memorial Day
- Friday, July 4, 2003 in honor of Independence Day
- Monday, September 1, 2003 in honor of Labor Day

Please do not fax any confidential information to the ACR on these days. As a reminder, you should also not fax confidential information to the ACR on evenings and weekends.

ARIZONA EMPLOYMENT OPPORTUNITIES

ACR Employment List

The Arizona Cancer Registry maintains a list of Cancer Registrars interested in temporary, contract, and full-time work. If a facility is interested in obtaining the list or if you wish to be placed on the list

of those interested in employment, please contact the ACR secretary at 602-542-7320. The Arizona Cancer Registry provides this informational list as a service to registrars and facilities in the state, and does not endorse or provide recommendations about individual registrars. Terms and conditions of employment must be negotiated between the hiring facility and the registrar.

Openings at Hospitals

St. Joseph's Hospital in Phoenix has a full-time opening for a cancer registrar. Contact Maria Owen at 602-406-3048.

Seminars and Meetings

Introductory Abstracting Workshop

Introductory Abstracting Workshop, presented by the Arizona Cancer Registry, will be held June 9-11 at Northwest Medical Center in Tucson. Contact Nancy Doll, RN, CTR at 602-542-7592. See the registration form on the next page.

NCRA Annual Educational Conference

National Cancer Registrars' Association 29th Annual Educational Conference will be held May 14-16, 2003 in Pittsburgh, Pennsylvania at the David Lawrence Convention Center. Registration information has been mailed to all NCRA members. Anyone interested can also find information and registration materials at the NCRA website, ncra-usa.org.

AJCC 6TH Edition Videotape Available

The ACR has available a copy of a videoconference presented in November, 2002 by the AJCC. The program is entitled "The Changing Strategies of TNM Staging: Introduction to the AJCC 6th Edition." The running time is 2 hours, and two continuing education credits are available from NCRA. This program was first presented by live satellite feed on November 21, 2002. Even if you did have the opportunity to attend the original program, you probably remember that there were numerous problems with the feed. And with the implementation of the AJCC 6th just around the corner, this would be a great time to cover the topic again.
Call or e-mail Nancy at the number over there...

FROM STEVEN ROFFERS, PA, CTR

Dear colleagues --
Plan to attend the next Principles and Practice of Cancer Registration, Surveillance, and Control training program -- August 18-22, 2003.
And also attend the following week, August 25-29, 2003, for the Cancer Case Abstracting, Staging, and Coding training program (loads and loads of hands-on abstracting, staging, and coding -- learn by doing!).
Complete details of these training programs, as well as the Advanced Cancer Registry Training Program, are available on-line at http://cancer.sph.emory.edu
Register soon as these highly acclaimed training programs fill up fast!
Take care,
--Steven
Steven D. Roffers, PA, CTR
Faculty, Dept. of Epidemiology
Rollins School of Public Health
Emory University

WHERE TO FIND US

Our address as of August, 2003 will be:
150 North 18th Avenue
Phoenix, AZ 85007-3228

NAME	PHONE	E-MAIL
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Hudson, Dina	542-3726	dhudson@hs.state.az.us
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Nguyen, Kim	542-7338	knguyen@hs.state.az.us
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Zubiate, Coleen	542-7329	czubiat@hs.state.az.us

Introductory Abstracting Workshop
June 9-11, 2003
Northwest Medical Center
Tucson, Arizona
Presented by the Arizona Cancer Registry

Agenda

Monday, June 9	Tuesday, June 10	Wednesday, June 11
• Cancer Registry, What and Why? • Major Players Involved in Cancer Data Collection • State Law • Who Reports • What is Reportable? • Casefinding • What=s In an Abstract? • General Abstracting Principles • Books Used in Cancer Registry • Case #1 Narrative	• Using The Books -ICD-O-3 -SEER Summary Staging Guide 2000 -AJCC Manual for Staging of Cancer, 6th Edition -ACR Coding Handbook (includes *FORDS*) -SEER Book 8 $ Case #1 Codes $ Case #2	• Abstracting From Medical Records (Finish Case #2 and #3) • Brief Overview of Secondary Abstracting Workshop -Overview of the RMCDS software -Updating the database and follow-up -Interaction between the ACR and reporting facilities -Critical data items

Registration Form

Name _____ **Credential**_____

Facility_____

Address (where information should be mailed to you)
_____

City_____ **State**_____ **ZIP**_____

Phone _____

Please mail or fax to:
Arizona Cancer Registry
1740 W. Adams, #410
Phoenix, AZ 85007
Attention: Nancy Doll, RN, CTR
Fax: 602-542-7362

This Workshop is Free to all Participants

This Month's Feature:

The Health Information Portability and Accountability Act of 1996
A brief history

(Note: The opinions and information in this article are mine alone and have not been reviewed or approved by anyone from the Arizona Department of Health Services)

When you read the stated intention of Public Law 104-191, also known as the Health Insurance Portability and Accountability Act of 1996, it sounds like they were creating health insurance nirvana. It is "an act to amend the Internal Revenue Service Code of 1986 to improve portability and continuity of health insurance coverage in the group and individual markets, to combat waste, fraud, and abuse in health insurance and health care delivery, to promote the use of medical savings accounts, to improve long-term care services and coverage, to simplify the administration of health insurance, and for other purposes."(1) That's the first paragraph of the law now known as HIPAA.

Because of our positions as workers in healthcare facilities, many of us don't realize that the vast majority of the HIPAA law has nothing to do with privacy of health information. The intent of this legislation was to make health insurance more affordable and more ***portable*** for Americans. It was intended to prevent people from being without health insurance or being denied coverage for pre-existing conditions when they changed jobs. It was intended to fend off fraud and abuse aimed at public and private insurers, and to change tax laws so that individual health insurance policies would become more affordable and health care savings accounts more useful. To some extent the goals of portability and affordability of insurance have been achieved. An excellent website from Georgetown University discusses your newfound rights in buying and keeping health insurance (www.healthinsuranceinfo.net), state by state.

But lying within the dense legalese that is HIPAA, just 14 pages of the 176 total pages of the document, is Title II, Part C. This section is named, of all things, "Administrative Simplification". And in that small section of the law are the requirements that, within 12 months after the passage of the law, standards be adopted for the generation and transfer of health information. That 12 month deadline came and went, and the responsibility for developing privacy standards fell to the Department of Health and Human Services in August of 1999.(2)(3) That's how the Privacy Rule was born. And if you haven't heard of the HIPAA Privacy Rule by now, you probably don't get out much.

The impact of the HIPAA Privacy Rule on the health care environment is difficult to overstate. As of this date, the Privacy Rule and its revisions have been published in at least five editions of the *Federal Register* and span hundreds of pages. Several state Medicaid agencies put a $10 million price tag on implementation, though various government-funded studies predict an overall cost savings over the next ten years.(4) The costs incurred are mainly administrative. The law requires designation of a compliance officer, training of all employees at covered entities, modifications to policies and procedures to reflect the rules, and development of systems to document compliance and facilitate individual complaints about violations.(5) Covered entities must also bear the cost of complying with standards for coding and transfer of billing and other data, as promulgated in part 162 of the Privacy Rule.(6) Compliance with standards for coding and electronic data transfer was required by October, 2002, though many organizations have sought and received one year extensions.(7) Compliance with remaining standards was required by April 14, 2003.

The scope of this newsletter and the activities of the Arizona Cancer Registry do not allow for us to interpret the HIPAA Law and the Privacy Rule. We are relying, as you should, on the opinions of standard setters in the cancer registry field and the compliance officers in our facility. We have received numerous inquiries with regard to transactions between the ACR and reporting facilities, and will attempt to address the questions in the next section, providing the answers that have been put forth by the American College of Surgeons, NAACCR, the NCRA, the Office of Civil Rights of the Department of Health and Human Services, and our own compliance officers.

Nancy Doll, RN, CTR

(1) Public Law 104-191, August 21, 1996
(2) Public Law 104-191, Title II, Section C, August 21, 1996
(3) Hodge, James G. Jr, Adjunct Professor of Law, Georgetown University. Letter to Holly Howe, Executive Director of NAACCR. July 13, 2001.
(4) 45 CFR, Parts 160 and 162.
(5) 45 CFR, Part 164.530
(6) 45 CFR, Part 162.
(7) Federal Register, Vol 68, Number 34, p. 8384, February 20, 2003.

HIPAA Q & A

This is a partial list of the questions we have received from registrars about the HIPAA Privacy Rule, along with answers gleaned from resources published by Cancer Registry standard setters. There are some questions that have not been answered yet, and they have been submitted to different sources. We will pass along answers when we get them.

1. **How does HIPAA affect a reporting facility's ability to conduct follow-up to external physicians (this appears to mean physicians not on the medical staff roster) within the state and outside the state?**
2. **How does HIPAA affect a reporting facility's ability to conduct follow-up to the specific individual?**
3. **How does HIPAA affect the ability of a reporting facility within the state to exchange information with another in-state reporting facility about a shared patient?**

This seemed like three versions of the same question, since it involves the transfer of protected health information between covered entities, so they are grouped together here. Please note that, in their original published form, some of the answers below also contain direct quotes from either the HIPAA Law or the Privacy Rule, but space and time do not permit the inclusion of all the citations of the text of the rules in this newsletter.

- *From NAACCR – "Although private practice physicians and hospitals are health providers, and thus covered under the provisions of the HIPAA privacy regulations, they may continue to provide cancer patient follow-up and treatment information to hospital cancer registries without patient authorization when both the physician and the hospital **has or had** a relationship to the patient.*
  Under the HIPAA Final Privacy Rule, private practice physicians may disclose confidential patient information to hospitals for the purpose of treatment, payment, or healthcare operations (quality assessment and improvement is considered a healthcare operation). A business associate agreement is not required between a hospital and physician for such purposes."
  "…as hospital cancer registries collect treatment and follow-up data in compliance with state law and for the for the purpose of "population-based activities related to improving health" this is permitted disclosure without requirement of patient authorization. It may also be noted that many hospital cancer registries collect this information for "conducting quality assessment and improvement activities", …and for "accreditation, certification, licensing or credentialing activities". All of these are specifically permitted (in section 164.501 of the Privacy Rule).
  *Note that section 164.506 (c) (4) specifically provides for the ability of one covered entity to provide an individual's protected health information to another covered entity, if the receiving covered entity **has or had** a relationship with the individual. This specific reference to the past tense is important since it means that a covered entity's ability to obtain information about a patient need not be 'cut off' if the patient no longer has a direct relationship with the covered entity.*
  *While exchange of treatment and follow-up information is permitted without patient authorization under the provisions described above, **an accounting of disclosure must still be maintained."***

- *From the American College of Surgeons' Commission on Cancer – Upon review, the College's answer is exactly the same (word-for-word) as paragraph two and three of the NAACCR answer above.*

- *From the National Cancer Registrars' Association – "Under the current August 14, 2002 'Final Rule', many of the cancer registry functions are being carried out under the 'operations' umbrella of HIPAA, regulations known as the '…consent for uses and disclosures to carry out **t**reatment, **p**ayment or healthcare **o**perations…' **(T/P/O)**. **(164.506, (a) (2) and (3) of 45 CFR).***
  'Operations' include 'quality assessment and improvement activities' and 'population-based activities related to improving health or reducing healthcare costs'. This allows hospitals and physicians to disclose protected health information, including first course of treatment and follow-up to each other for specified healthcare operations, provided that both covered entities have a relationship to the patient. Patient follow-up many years after treatment (or encounter) remains an area that needs further clarification by the OCR in future modifications of the 'Final Rule'."

(Continued on page 6)

(Continued from page 5)

4. How does HIPAA affect the ability of a reporting facility to exchange information with an out-of-state reporting facility (including other state central cancer registries)?

- *From NAACCR - …with regarding to reporting to out-of-state central registries - "it is not prohibited. In fact, the definition of a public health entity was broadened in the section 'Uses and Disclosures for Public Health Activities', which states specifically, '…We broaden the scope of allowable disclosures…by allowing covered entities to disclose protected health information not only to U.S. public health authorities but also, at the direction of a public health authority, to an official of a foreign government agency that is acting in collaboration with a public health authority.'" (45 CFR 164.512)*
  With regard to exchange of information of protected health information between two covered entities in different states, this is not specifically addressed by any of the standard setters, but it would seem that the answer would be the same as it was for questions 1-3, as long as the information exchange was for the same purposes (i.e. population-based activities related to improving health).

5. In addition to case reports sent to the ACR, would hospitals also be required to track all updates and corrections sent to the ACR? This is presumed to be a reference to the Privacy Rule requirement for an Accounting of Disclosure.

- *From the California Cancer Registrars' Association – "Yes, either the hospital cancer registry or another department within the hospital must keep an accounting. The accounting must include for each disclosure:*
- S *The date of the disclosure.*
- S *The name of the entity or person who received the protected health information and, if known, the address of such entity or person.*
- S *A brief description of the protected health information disclosed.*
- S *A brief statement of the purpose of the disclosure that reasonably informs the individual of the basis for the disclosure, or in lieu of such statement, a copy of a written request for a disclosure under §164.502(a)(2)(ii) or 164.512, if any."*

Once again, the CCRA was the only entity to address this specific question, and they felt it applied to "new case reports, follow-up records, correction records, deletion records, pathology only cases, tumor board only cases and consultation only cases."

6. These next three questions are from the ACR staff, and fall into a similar category: How will HIPAA affect our ability to perform audits at facilities? When the ACR performs case-finding audits medical records are reviewed to determine if they contain reportable cases. Inevitably, staff will need to view records with cases that are not reportable.

7. How does HIPAA affect our ability to review medical records in order to perform data collection?

8. How does HIPAA affect our ability to perform data collection at pathology laboratories.

- *The question was phrased this way in the CCRA document: Are reporting facilities required to permit access to confidential patient records by state cancer registry staff for the purposes of assuring completeness and accuracy of cancer reporting? And the answer was: "Yes, if state law permits the state cancer registry to perform these audits." (Refer to Arizona Administrative Code, Title 9, Chapter 4, section 403 for rules regarding allowing access for data quality assurance.)*
- *From NAACCR – this answer was in response to a question about whether pathology labs would be able to continue to send new cancer case information to the state cancer registry: "Yes. Public health reporting under the authority of state law is specifically exempted from HIPAA rules.*
- *From the ADHS Director's Communication – "The Arizona Department of Health Services certifies that it is a public health authority and health oversight agency as mandated by the State of Arizona. As such, **FEDERAL LAW, INCLUDING HIPAA, DOES NOT RELIEVE ANY INDIVIDUAL OR ENTITY FROM A CONTINUING DUTY TO REPORT OR DISCLOSE PUBLIC HEALTH INFORMATION AS REQUIRED BY ARIZONA LAW."** (Their emphasis) The protected health information… received by the ADHS include(s):*
  (2) Information and records related to public health surveillance…and
  3.(a) audits…(c) inspections…(f) other activities necessary for oversight…

9. Some HIPAA administrators at hospitals have recommended that the reporting facilities no longer fax protected health information in keeping with their policy on fax use in non-emergent situations.

10. How will HIPAA affect the ability of the ACR

(Continued on page 7)

to FAX protected health information to reporting facilities, including physicians?

- *This response was found in the FAQ section of the Health and Human Services, Office of Civil Rights website, and is in response to a question about whether a physician could FAX protected health information to another physician: "The HIPAA Privacy Rule permits physicians to disclose protected health information to another health care provider for treatment purposes. This can be done by fax or by other means. Covered entities must have in place reasonable and appropriate administrative, technical, and physical safeguards to protect the privacy of protected health information that is disclosed using a fax machine. Examples of measures that could be reasonable and appropriate in such a situation include the sender confirming that the fax number to be used is in fact the correct one for the other physician's office, and placing the fax machine in a secure location to prevent unauthorized access to the information. See 45 CFR164.530(c)"*

Works Cited:

American College of Surgeons, Commission on Cancer. Frequently Asked Questions (FAQs) Received by the COC Related to HIPAA. November 11, 2002.

Arizona Department of Health Services, Office of the Director. Letter to Health Care Providers. April 11, 2003.

California Cancer Registrars' Association. Frequently Asked Questions and Answers About the HIPAA Privacy Rule Regarding Hospital-based Cancer Registry Operations. April 8, 2003.

Chufar, Daniel. HIPAA at a Glance for Cancer Registrars. National Cancer Registrars' Association. Not dated, currently posted on NCRA website.

Department of Health and Human Services, Office of Civil Rights Website. Health Information Privacy Frequently Asked Questions.

North American Association of Central Cancer Registries. Frequently Asked Questions and Answers about Cancer Reporting and the HIPAA Privacy Rule. March 31, 2003.

Do yourself a favor…

If you have the time and opportunity to print in your workplace, start yourself a HIPAA notebook. The official documents, as published in the **Federal Register** are cumbersome, but with some time and effort, you really can become familiar with them and will at least know where things are.

- First go to an online site where you can read and print out documents from the **Federal Register** at *http://www.access.gpo.gov*. Print out the law, dated August 21, 1996. Print out the final rule, dated August 14, 2002. There were "proposed" and "final" rules in the interim, but the volume of paper you're already using will be impressive. Don't get bogged down. In 2003, there were final rules published on February 20th (security standards); March 20th (notice of where complaints about violations of the Privacy Rule should be submitted); April 17th (notice of civil penalties to be imposed for violations of the Privacy Rule). Consider printing these. From time to time, additions and modifications to the Privacy Rule will be published and can be found by doing a search of this website.
- Go to the website of the Department of Health and Human Services Office of Civil Rights (*http://www.hhs.gov/ocr/hipaa/finalreg* and print out the unofficial (but much more readable) version of the final rule entitled **Standards for Privacy of Individually Identifiable Health Information.** The same website, but in a different area (*www.hhs.gov/news/facts/privacy)* also contains an excellent 4-page fact sheet

Additionally, information can be gleaned from the following websites and resources:

North American Association of Central Cancer Registries *(www.naaccr.org).*
National Cancer Registrars Association *(www.ncra-usa.org).*
American College of Surgeons, Commission on Cancer *(www.facs.org).*
American Health Information Management Association *(www.ahima.org)*
Arizona Department of Health Services *(www.hs.state.az.us).*

Fritz, April. "HIPAA Revisited: The 'Final-Final' Rule". The Resourceful Registrar. Journal of Registry Management. Winter, 2002 (29:4).

RMCDS MOVES TO ACCOMMODATE HIPAA CHANGES

Rocky Mountain Cancer Data Systems Assistant Director, Larry Derrick, issued a memo to the Arizona Cancer Registry in April 2003 summarizing the changes made to the RMCDS software in an effort to aid registries in their compliance with the HIPAA Privacy Rule. Here are the newly added features:

1. There will be a new option in the software that will allow a hospital or central registry to designate users as "registry" or "non-registry". The add/update program is being modified as well. It will now create an automatic entry in a log when "non-registry" individuals access cases. Larry says, "we are assuming that they have been given permission to access cases and have been given a login ID that is marked as 'non-registry'." If registry staff members access cases in the course of their normal work, a log entry will not be made. If a hospital or central registry feels that HIPAA requires the monitoring of anyone, including registry staff, who accesses cases, this can be done by designating everyone as "non-registry".
2. When listings that contain confidential information are created, the creator of the report will be asked if it is for registry operations (administrative reports, qc reports, etc) or for disclosure outside the registry. If the report is for use outside the registry, a log entry will be made identifying the user that created the report, the date of the report, the type of the report (1-line listing, 2-line listing, chosen variables, etc.) and the purpose/destination of the report. The subset that was used for the report will be saved to allow determination of which records were included. All of this information will be gathered from a pop-up window. If an organization feels that any list with confidential information has to be logged, then they can specify that all reports are for use outside the registry. A similar procedure occurs whenever an export file is created (NAACCR incidence, NAACCR confidential, NAACCR full, or a custom ASCII record).
3. Copying a subset to a subsystem follows the same procedure as item #2.
4. When hospitals send cases to the state, or send cases to NCDB, a log entry will be made out similar to the ones described above. The cases are also marked in the master record for easier tracking of cases sent.
5. When central registries send cases to NAACCR or NPCR, the same procedure as in #4 will occur.

Larry adds that a program is being developed that will allow the registry to query all the reports, subsets, etc that were generated containing information about an individual patient. For example, if Bob Smith comes to the registry and asks to know if and when information about him was released, the registry should be able to create a query and give him a report containing the type of information that was released, who the report went to, and the date. The query would be capable of going back six years, but would not search subsets prior to April 14, 2003.

Larry adds, "If you see a loophole in our approach or have a different interpretation of HIPAA, or have some suggestions regarding this and how to improve it and make it simpler, please contact me and we will discuss it."

He can be reached at:
larry.derrick@m.cc.utah.edu or (801) 581-4307

MAKING A SHORTCUT ICON FOR RMCDS WINDOWS

The fall, 2002 edition of Rocky News included information about how to create a shortcut icon for RMCDS Windows and put it on your computer's desktop. Here's how…

1. Look to see where RMCDS is installed on your system. On the opening screen of RMCDS, under the picture of the mountains and under today's date, you will find the address of RMCDS on your hard drive. It will look something like this: n:\rmcds\programs. This means that the program is on you r "n" drive.
2. To create the icon, double click on the My Computer icon on your desktop. Find the drive you have identified as containing RMCDS (in this case, the n: drive) and double left-click it.
3. Double left click on the "RMCDS" folder and then find the "programs" folder.
4. Double left click on the "programs" folder and then search for a program called **w_menupg.exe**. Single left click once on **w_menupg.exe** to highlight it, then right click once. A drop-down menu will appear. Left click once on "create shortcut."
5. This will create a new icon and put it at the end of all your other programs in the folder. You can then click and drag the icon out to your desktop.
6. You can then rename the icon by single-clicking on it to highlight it, then right-clicking once. Left click once on "rename". The label part of the icon will be highlighted now. Type the new name you want to use, then press enter.
7. Now you should have a new icon for RMCDS on your desktop!

This was summarized and paraphrased from an original article from Mark Hunzeker of RMCDS.

Data Quality Issues

As a result of an ongoing review of the FORDS Manual, the following two questions were submitted to the Inquiry and Response system at the ACOS:

Question #1
Why is Bowen's disease used in FORDS, page 94, as an example for the field Behavior Code? This will not be an eligible histology for approved programs with the implementation of FORDS.

In Reply:
You are correct. Bowen disease, 8081/2 is not an eligible histology for approved programs beginning January 1, 2003 and will be dropped from the examples on p. 94 of FORDS.FORDS page viii was used as the resolution source.

ACR NOTE:
This question was asked in light of the decision by both the College and the Arizona Cancer Registry to discontinue collection of all basal and squamous cell carcinomas of the skin, no matter what the stage of disease at diagnosis. With cases beginning January 1, 2003, BCC and SCC of the skin will no longer be collected. Previously accessioned cases (prior to 2003) should remain in the registry and normal follow-up should continue.

Question #2
For coding tumor size in FORDS, the instructions on page 100 state that mixed in-situ and invasive tumors should be coded 999, for unknown size. Won't this increase the number of breast cases with unknown tumor sizes?

In Reply:
If both an in-situ and an invasive component are present and each is measured, code the size of the invasive component even if it is smaller. Code 999 only if one size is given for mixed in-situ and invasive tumors.
FORDS page 100 was used as the resolution source.
Was I the only one who didn't know this rule? Georgia and Brenda knew it...Based on a review of some 2001 cases, I am not alone in my ignorance. I pulled a random sample of 2001 breast cases and had a look at them to see if anyone else has been coding tumor size in this situation. Alas, I am not the only one who has made this mistake. What I found in a review of 75 randomly selected cases was:

- that twelve of them contained mixed in-situ and invasive histologies.
- seven of those twelve cases had only one tumor size identified in the path report narrative, and it did not refer specifically to the invasive portion of the tumor.
- The reporting registrars used that size, as stated in the narrative, to code the size of the tumor.

Thankfully, this rule is now clearly stated in FORDS. Remember to code tumor size only when it refers strictly to the invasive tumor.

The following two questions were submitted to the American College of Surgeons Inquiry and Response System by Kyle Coppola, RHIT, CTR of the Mayo Clinic. She was kind enough to forward them to us at the ACR.

Question #1
If a patient underwent dilatation for only palliative purposes for a distal esophageal cancer, no biopsy or stent placed, is it coded non-cancer directed surgery 07?
In Reply:
Yes, code this 07, non-cancer directed surgery.

Question #2
How is someone of Arabic descent, such as from Lebanon or Iraq, coded?

In Reply:
According to the US Census Bureau, which SEER follows in order to have matching populations for the denominator for incidence rates, people of Middle Eastern and North African descent, including Arabs, Lebanon, Iraq, Israel, Egypt, Morocco and many other countries, are to be coded as 01White. They are not Asian because they are not on the western side of the Caucasus Mountains. April Ftitz, SEER curator
Standards, Volume II page(s) ROADS p. 73, FORDS p59-64 was used as the resolution source.

What Do You Think??

How about participating in an informal survey??
Please answer the following question:
Primary: Prostate
Pathology report reads: Grade 3 of 4 adenocarcinoma, Gleason 3+4=7
What is the code for grade?
Write your answer on the back of a $20 bill and send it to Nancy at the ACR (or e-mail me if you're short on cash).

DATA ANALYSIS AND SPECIAL PROJECTS

ACR/GILA RIVER DATA EXCHANGE

Because Arizona has 17 Sovereign Indian Nations within its borders, the Arizona Cancer Registry (ACR) has the unique responsibility to report on cancer cases diagnosed among Native Americans who reside on those reservations. The New Mexico Tumor Registry (NMTR) has for many years traveled into Arizona to collect the information among Native Americans who reside on the reservations. The ACR has a long-standing written agreement with the New Mexico Tumor Registry (NMTR), and the Indian Health Services (IHS) to exchange Native American information.

As a result, the Gila River Indian Community approached the ACR within the past year to assist them in identifying those individuals who reside in the Gila River Community and who are members of that tribe. This presented a unique opportunity to the ACR to perform a data exchange with the Gila River Public Health Department to identify the tribal affiliation of Arizona Native Americans in Gila River.

The first data exchange was performed in July, 2002, and was very successful. The ACR found updated tribal information, updated residence information and a few other demographic factors on the cancer cases, and Gila River found the members of their community who have been diagnosed with cancer.

We anticipate other tribes to follow Gila River's lead and ask for similar data exchanges with the ACR in the future. The ACR looks forward to using the data in this unique way to strengthen connections with the Native American Tribes in Arizona.

Amy Stoll, MS, Epidemiologist,
Arizona Cancer Registry

From: Ten Years of Progress: The National Program of Cancer Registries, Commemorative State Highlights. CDC Cancer Prevention & Control Website

STUDIES OF CANCER SURVIVORS

The Study of Cancer Survivors-II is being wrapped up this month. A total of 446 patients were consented and are receiving questionnaires from the American Cancer Society. Pepper Cothran has been working steadily on follow-up calls.

Plans for the Study of Cancer Survivors-I are underway and consenting may begin as early as this summer. SCS-I is a prospective, longitudinal study that will follow patients from one year after diagnosis until ten years after diagnosis. It is thought that there are significant changes in quality of life with each passing year, and one of the aims of SCS-I is to look at these changes.

DATA COLLECTION & EDITING

FROM BRENDA SMITH...

New Case Print List

During our hospital processing, we have noticed that hospitals are not enclosing a new case listing with their backup. Due to our paperless registry, we need (from all registrars) listings of all new cases included in their monthly backup. This enables ACR to know if all cases are being reported and not missed.

As a reminder…
all 2002 cases are due to be submitted to the ACR by July 1, 2003.

Conversion to FORDS

Reporting facilities should make the abstraction of cases diagnosed on or before December 31, 2002 their highest priority. More news about the conversion will be in the next CNV (if not before). If you have questions you would like to have answered about the conversion, send them to me at ndoll@hs.state.az.us

ARIZONA CANCER REGISTRY MAKES NAACCR CERTIFICATION

The North American Association of Central Cancer Registries known as NAACCR is a professional society whose members are interested in the development and application of cancer registration and morbidity survey techniques to studies of defined population groups and to the conduct of cancer control programs. Many cancer registries, including the Arizona Cancer Registry, governmental agencies, professional associations, and private groups in North America interested in enhancing the quality and use of cancer registry data are members of this organization.

The Certification Committee of the NAACCR has established a process by which full member registries can receive an evaluation and feedback regarding their achievements in the areas of case ascertainment, completeness of information on critical variables, data accuracy, and timeliness. By using this established criteria, population-based registries can be recognized for a Gold or Silver Standard in these areas. The ACR participated in the NAACCR Call for Data 2003. Registries were encouraged to submit their 1995 – 2000 data. The 2000 data was reviewed for certification. The Arizona Cancer Registry (ACR) was recognized for achieving the Silver Standard. The registry has participated and been certified for five of the six years since certification started. The results follow.

Summary of Certification Measures				
Registry Elements	Gold Standard	Silver Standard	ACR Actual Measure	Standard Achieved
1. Completeness of case ascertainment	95%	90%	91.47%	Silver
2. Completeness of information recorded – Missing/Unknown				
Age				
Sex	<=2%	<=3%	0.01%	Gold
Race	<=2%	<=3%	0.03%	Gold
State/Province & county	<=3%	<=5%	1.35%	Gold
	<=2%	<=3%	0.03%	Gold
3. Death certificate only cases	<=3%	<=5%	1.81%	Gold
4. Duplicate primary cases	<=1 per 1000	<=2 per 1000	0.13 per 1000	Gold
5. Passing EDITS	100%	97%	100.0%	Gold
6. Timeliness	Data submitted within 24 months of close of accession year.	Gold		
Certification Status	Silver			

The ACR recognizes the contribution all reporting entities make toward this progress. We thank hospital cancer registries, clinics, and physicians for continued collaboration in the effort of timely, complete, and quality reporting.

Address Info here

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CANCER NEWS AND VIEWS

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